# Emergency Preparedness Toolkit for Families of Children and Youth with Special Health Care Needs (CYSHCN)

**For Personal and Community Emergencies**

CATAWBA
GASTON
CLEVELAND
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INNOVATIVE APPROACHES

Children with special health care needs may rely on medications, equipment, routines, or specialized care that can be disrupted during emergencies such as storms, power outages, transportation delays, or sudden medical situations. This toolkit and Child Emergency Support Plan helps families prepare ahead of time so others can quickly understand and support their child/youth's needs.

**Instructions: The items below are documents that families can prepare in advance to share with emergency responders and other people in your child/youth's life. This can include babysitters, school staff, therapists, extended family, direct support professionals, and others who regularly care for your child/youth.**

The Child Emergency Support Plan is a fillable document that provides important information about your child to anyone who may need to care for them during an emergency. It can help caregivers, emergency responders, and medical professionals understand your child's needs and provide the best possible care. Sign up for emergency alerts in your county: **County Emergency Management Agencies**.

Encourage friends, family, and neighbors to sign up for regional public emergency alerts. You will be asked to enter your personal contact and address information. This data is private and protected.

Other suggestions:

- Follow Trusted Sources for Information
- Tune into local emergency radio stations
- Find your local AM and FM stations
- Consider purchasing a NOAA Weather Radio
- Weather service warnings and other hazard info 24/7
- Visit **Weather.gov/NWR**
- Follow local television
- Visit **https://www.readync.gov/** for important weather related updates and strategies

## 1. Personal Emergency Medical Identification

Create a quick-reference document, such as **ECAC's Child Emergency Support Plan**, that can be shared with emergency responders, caregivers, or medical staff. Include a current photo of your child if possible. In addition to the quick-reference document, please include a photo copy of the child/young adult's immunization records, insurance cards, and any legal paperwork. Important legal documents may include healthcare power of attorney, guardianship, DSS placement, adoption/custody paperwork, and instructions for care decisions in the event of parent or guardian incapacitation, absence, or deportation. You will also want to include any medical specific ID cards (Non-MRI safe implantable device, risk of adrenal crisis, etc.) with this document. Many online "my charts" have an option to print your health summary. This may contain health conditions, medications, allergies, etc. that could be printed and kept with this document also.

**Tip: Update this document regularly (ideally every 6 months or as changes occur). Keep copies in your emergency kit, vehicle, child's backpack, with trusted caregivers, etc. Use a specific colored waterproof folder. Keep digital copies on your phone or cloud storage. When appropriate, take photos of important legal documents so you can access and view them on your phone at any time.**

Options for sharing this quick-reference document include:

- Emergency information card printed out
- Durable tag with a QR code attached to wheelchair, backpack, or car seat
- Laminated QR code linked to emergency medical information
- Medical ID bracelet with QR code

## 2. Emergency Contact List

Maintain an up-to-date list of people who can help during emergencies. This can include any backup caregivers and reliable individuals who are familiar with your child. Many people list family members, providers, therapists, clergies, and even trusted neighbors. You can also include case managers or home health agency contacts for your child. A “neighbor disclosure card” may be helpful if you have a child who is prone to wander. It can give neighbors tips and advice on how to help. Include this on the quick-reference document.

Another option is to list **In Case of Emergency (ICE)** contacts in your phone. See below for common instructions.

- **On iPhone**: Open the Health app, tap your profile picture, and select Medical ID. Tap "Edit" and scroll to the "Emergency Contacts" section to add your contacts. Make sure the "Show When Locked" toggle is turned on so responders can see it.

- **On Android**: Go to Settings, scroll down to Safety & Emergency (or Passwords & Security), and select Emergency Contacts. You can add contacts from your address book so they are easily viewable on your lock screen.

Some phones also allow you to store emergency information under a notes section with your ICE contacts. Consider adding brief information like blood type, medical conditions, allergies, and medications for yourself and common people (i.e. children) who are with you. Include a brief description of what each person looks like.

A Legacy Contact may be designated to access your phone in the event of your death. See below for common instructions.

- On iPhone: Go to Settings > [Your Name] > Sign-In & Security > Legacy Contact.
- On Android: Go to your Google account settings and search for Inactive Account Manager

**3. Preferred Hospitals and Medical Facilities**

List hospitals or clinics familiar with your child's condition. This can include your preferred hospital or provider network. It also may include specific hospitals and locations that manage your child's specific condition(s. Include directions and approximate travel time from your home. It is a good idea to include a map print out or link to show how to get there.

**4. Medical Equipment and Power**

If your child uses equipment that requires electricity, plan ahead by creating a list of equipment that requires power and a written plan for recharging before power outages occur. Know the battery life of each device and charge it before the inclement weather is expected. It is a good idea to keep spare hearing aid batteries, glasses repair kits, and other easy to store items within your emergency supply kit. Keep extra batteries for other durable medical equipment if possible. Consider a backup power option such as solar, gas, or propane generator. Some "power banks" and other devices can be charged ahead of time and utilized for recharging cell phones, flashlights, and other smaller items. For any backup power option, remember fuel storage, safety, and stability. Always read the owner's manual and follow all written instructions for equipment use and charging. Some equipment also contains car chargers and inverters. Know the required minimum amps/power utilized to charge. Remember to follow all safety instructions.

**Tip: Ask your durable medical equipment (DME) supplier or doctor about non-power options such as portable canned oxygen, gravity feeding bags, or Dial-a-Flow® IV tubing to include in your emergency kit.**

**WARNING: CARBON MONOXIDE DANGER**

**Never use a fuel-powered generator indoors, inside a garage, basement, shed, or any enclosed space. Never place a generator near doors, windows, or vents where carbon monoxide gas can enter the home. Generators produce carbon monoxide, an invisible, odorless gas that can cause serious illness or death. Always operate generators outdoors in a safe, well-ventilated area away from the home. Never run a vehicle inside a garage or enclosed area when using a car charger or inverter. Keep battery-operated power stations indoors, as exposure to outdoor conditions can damage them.**

**Tip: Check carbon monoxide and smoke alarms regularly! Monthly: Press the test button on every unit to make sure the alarm sounds properly. Twice a year / Annually: replace batteries once or twice a year. Clean yearly: Gently vacuum or blow out dust from the cover and sensor slats at least once a year.**

Financial assistance may be available to assist with purchasing items for emergency preparedness for families who have children and youth with special health care needs. See our resources section for additional information.

**Tip: If you have a generator, plan a practice day to see what your generator will safely run and for how long before running out of fuel. Know your estimated fuel usage (if any) per day before an emergency. Read the owner's manual and know how to operate safely (water resistant, types of allowable drop cords, how far from home, etc.).**

### 5. Communication Support

If your child has communication challenges, create a backup communication plan. This may include picture communication boards or laminated cards for basic needs (hungry, thirsty, pain, bathroom, etc.). Planning for back up charging of Augmentative and Alternative Communication (AAC) devices may include the use of power banks or generators. Many speech apps offer “free trials” that can be downloaded to another device in the event the main AAC device becomes unusable. Communication support planning should include written instructions for how your child communicates in the event you are not with your child. A list of your child’s common spoken vocabulary and/or sign language can be helpful. Include what each word looks/sounds like to them. Include communication your child knows both expressively and receptively.

**Instructions: The items below are items that families can purchase and prepare in advance to have in a kit or “go bag” for emergencies involving sheltering in place or evacuations.**

### 6. Emergency Supply Kit

Prepare a kit that can be quickly taken during an evacuation or for sheltering in place. These are some items to consider including:

#### Food/Water

- 1 gallon of drinkable water per person and pets per day (more if on well water)
- Pet food
- Snacks or special diet items
- Minimum of 3 days up to 2 weeks of shelf-stable foods each person likes and will eat

## Household Items

- Manual can opener
- Battery packs, chargers, power banks
- Phone charger
- Portable radio (hand crank or battery operated with extra batteries)
- Flashlight
- Extra clothing
- Blankets and pillows
- Hygiene supplies
- Toiletries
- Pliers/wrench (in case water/gas needs to be shut off)
- Local maps
- Matches (in a waterproof container/bag)
- Cash
- Shelter in place supplies such as tarps/tents/duct tape
- Toys and games including special comfort items/sensory items
- Baby wipes
- Hand sanitizer

## Disability/Medical Supplies

- Medications (including prescriptions if possible)
- Medical supplies (feeding tube supplies, catheters, etc.)
- Copies of medical and other important documents
- Communication tools (printed picture cards or back up AAC batteries)
- First aid kit
- Dust and/or surgical masks
- Clearn panel mask for lip reading

**7. Sensory and Regulation**

Emergencies can disrupt routines and cause sensory overload. Prepare items that help your child stay regulated and include them in your emergency kit where appropriate. These items may include noise-cancelling headphones, fidgets/sensory toys, comfort items (blankets, stuffed toys, etc.), weighted blankets/vests, or favorite calming activities. A list of behavioral de-escalation techniques including what helps, what doesn’t work, and any known triggers can be helpful also.

**Instructions: The listed items below are things you will need to plan/prepare for in advance. This is recommended to be written and shared with regular and back up caregivers.**

### 8. Medication Preparedness

Plan for medication disruptions during emergencies. In the past, there have been flexibilities around medications in times of disasters, but there is no guarantee this will be the case in future emergencies. Try to keep at least a 7-14 day supply of medication if possible. This may mean talking with your child's provider about how to ensure this amount of medication is on hand (especially with controlled substances and specialty drugs). Maintain and check expiration dates for backup medications if prescribed (example: emergency steroids, rescue meds for seizures/asthma/etc.).

Store medications safely and follow any temperature or refrigeration requirements. Know which pharmacies carry your child's medications, and keep copies of prescriptions when possible. Talk with your child's doctor ahead of time about what to do if medications run low or are unavailable during an emergency. Ask about possible alternative medications, what each medication is used for, and whether any medications can be safely reduced, delayed, or temporarily stopped if supplies are limited. Do not reduce, skip, or substitute medications without guidance from your child's health care provider or pharmacist.

Keep insulated bags and ice packs ready in case you need to keep medications or supplies cold during a power outage. If your child uses durable medical equipment (DME), try to keep extra supplies on hand. Ask your DME company if they can provide samples, backup supplies, or spare items for things such as feeding tubes, respiratory equipment, and incontinence supplies. You can also talk with your child's health care provider, pharmacist, or DME company about safe alternatives for medications, equipment, or supplies that may be difficult to get during an emergency.

**Tip: Check with pharmacies to see if they provide medications in advance in the event of a natural disaster emergency. After the event, there may be flexibilities around refilling sooner or at a different pharmacy. Check with your doctor, insurance provider, or pharmacist for support.**

**TIP: Know North Carolina's emergency refill rule. Under a North Carolina Board of Pharmacy rule, 21 NCAC 46 .1809, a pharmacist who cannot reach your prescriber may (but is not required to) dispense a one-time emergency refill of up to a 30-day medication supply, as long as the medication is essential to maintaining life or continuing therapy for a chronic condition. This rule doesn't cover Schedule II controlled substances, but it covers many maintenance medications.**

### 9. Vacation and Travel

Ensure your family knows how to access medical care and stay healthy away from home. Print information before leaving home:

- Health Summary or "Problems List"
- Treating specialists
- Medication List
- Equipment used

**Tip: You can notify cruise, flight, or boat attendants that you have this information for a loved one with a disability in your carry-on bag. You can also advise them if the person will need assistance with emergency exits due to mobility or sensory concerns. This information can also be provided to a treating physician in the event of an emergency visit while at the vacation destination. List any potential behaviors the child may exhibit and how to help in an emergency situation.**

**KNOW:**

- Locations of emergency rooms and medical facilities along your route and near your destination
- Write down the address where you are staying. Keep it where everyone can see it in case someone needs to call 911
- Pharmacy location that accepts your insurance (open 24/7 preferred)

**BRING:**

- Enough medication for 3-4 days longer than expected duration of trip if possible
- Back up Durable Medical Equipment (DME) (i.e. extra suction tubing, additional nutrition supplies for G-tube, nebulizer tubing, etc.)
- Power cords/batteries for all DME

**Tip: Plan to complete these items 30-60 days before you intend to travel to allow time in case you need a health provider to print your health summary for you. This can take 7-10+ business days depending on the office and how much advance notice they require. There may also be a fee.**

**Ask your provider ahead of time if there's an "after-hours physician call line" in the event a treating emergency room physician needs to speak to your child's specialist. Notify the agency you are traveling with about your child's disability or special health care need. Consider bringing a walkie-talkie if you will be in a crowded environment, such as on a cruise or in a park.**

## 10. Painting the Big Picture

Children benefit when the adults in their lives are able to see “the big picture” by understanding them as unique individuals. Parents and other caregivers help to “paint the big picture” when they share who their child is, what they can do, and how others can relate and respond to the child. It is a good idea to describe your child. This can include things others should know about your child and anything responders or caregivers should do first. Click on the picture below or scan the QR code to access ECAC’s Painting the Big Picture document.

1-800-962-6817 | ecac@ecacmail.org
www.ecac-parentcenter.org

# RESOURCES

Use the links below to jump to that section of the document.


- Nationwide/State Resources
- Financial Resources
- Social Stories
- Cleveland, Gaston, Lincoln & Catawba Specific Resources
- Local Resources by NC County
- Videos
- Resources for Medical Providers


## Nationwide/State Resources

Contact your local Emergency Management Coordinator or your Department of Social Services for information about your county's specific emergency or natural disaster plan, often called a "mass care plan," and for information on who to contact ahead of time to see if a shelter can meet the needs of your child with special health care needs. Please be advised to call 911 in the event of a true emergency. Emergency shelters in your county will determine if they can safely meet your/your child's medical needs on a case-by-case basis.

Your local fire department may be able to assist with providing carbon monoxide and/or smoke alarms if cost is an issue. Reach out to them directly to ask if they can provide assistance.You can also check with your child's case manager if your child has Medicaid. They may be able to assist with purchase of carbon monoxide and/or smoke alarms as well.

**NC Emergency Management Agency Directory**: You can click the link and sign up for emergency alerts for many counties. Some also allow you to check if you'd need special assistance in the event of a large-scale emergency.

You may contact your Emergency Management Coordinator or your communications director for information on how to "flag" your home as having someone with a disability or special healthcare need staying there.

You can also contact your emergency management coordinator and local power provider to notify them if anyone in the home uses essential powered medical equipment. Your power provider may require a physician to sign paperwork confirming your dependence on powered medical equipment. They may also provide advance notice of planned power outages. Check with your power provider to learn about their requirements and notification procedures.

Below are links to additional helpful resources:

- **Fema Mobile App**
- **The American Red Cross** has resources about disaster safety for people with disabilities:
  - **Being Prepared Means Planning Ahead**
  - **Create Your Emergency Plan in Just 3 Steps**
  - **Red Cross Mobile App**
- **Hopeforce International Disaster Response:** This site has information on specifics of water planning for special needs, disaster preparedness, and more for families of children and youth with special health care needs (CYSHCN).
- **BC Centre for Ability Emergency Preparedness for Children with Special Needs:** This is a shortened personal profile for use during emergencies.

- Family & Community Resources from **Region V for Kids Pediatric Disaster Center of Excellence**

- The **Centers for Disease Control and Prevention** (CDC) have many resources about caring for children with special health care needs and disabilities during a disaster:

  - **Children and Youth with Special Healthcare Needs in Emergencies**
  - **Make an Individual Emergency Plan**
  - **Safety Plan Considerations for Children with Disabilities**

- **Ready.gov**, from the Department of Homeland Security, offers disaster preparation resources in multiple languages.
  - **Standard Emergency Supply Kit** from **Ready.gov** available in English, French, Arabic, Spanish, Tagalog, and Korean
  - **Disaster preparedness for kids and teens**
  - **Emergency preparedness for people with disabilities**
  - **Are you Ready Guide**

- **Be Prepared in Case of Emergencies** - Courageous Parents Network

- **Emergency Planning for Students with Disabilities A Resource Document (PEATC):** This is a resource specific to Virginia however there are good questions to ask at IEP and 504 meetings including examples of emergency accommodations that may be included within your child's IEP or 504.

- **Family Voices - Preparing for Emergencies: Tips for Families**

- **How to Build a Disaster Emergency Kit or "Go Bag" for Your Family - American Academy of Pediatrics**

- **MyID** is a medical profile which can be accessed anywhere, anytime using bracelets, sticker kits, wallet cards and an app on your phone. This works through a QR code linked to your child's information that parents/guardians can enter. It has a free option and low cost items for purchase with the QR code already on it.

Some counties maintain a "special populations" registry to assist in providing services during disaster or emergencies that may impact you and your location based on your specific needs.

- **Disability Advocacy Center**

## Financial Resources

- **First in Families:** This organization serves families based on self-identified needs. Visit their website or reach out to your chapter for additional information. Contact phone number: 704-689-6648
- **ECAC Grant List for Families**
- **Low and No Cost Preparedness**

## Social Stories

- **Hurricanes, Fire Drills**
- **Safety and Emergency Preparedness Drills**
- **Lockdown Drills at School**
- **Emergency Services (Police Officers, Firefighters and Paramedics)**

## Cleveland, Gaston, Lincoln, & Catawba Specific Resources

- **Vaya Partners**
  - Behavioral Health Crisis Line: 1-800-849-6127
  - Member and Recipient Services Line: 1-888-235-HOPE (4673)
  - Provider Support Line: 1-866-990-9712

- **First in Families:** This organization serves families based on self-identified needs. Visit the Foothills Chapter website for additional information.

- Foothills (Cleveland/Gaston/Lincoln/Catawba) region phone number: 704-689-6648
- Foothills (Cleveland/Gaston/Lincoln/Catawba) region email address foothills@fifnc.org

**CATAWBA**

- **Project Lifesaver** - Program designed to assist in locating individuals who may be at risk of wandering or becoming lost, including individuals with conditions like Autism, Dementia, or Alzheimer's disease
  - No charge for individuals with Autism.
  - A $20 fee applies for individuals with Dementia or Alzheimer's disease unless the individual is unable to afford the fee
  - Free battery replacement visits are provided as needed to help ensure equipment remains operational.
  - Contact the Catawba County Sheriff's Office (828-464-5241) and ask to speak with the Project Lifesaver Coordinator

- **Access and Functional Needs Registry** - The Catawba County Special Needs Registry allows individuals and families to voluntarily provide information that may assist emergency responders during an emergency. Information may include:
  - Medical needs
  - Disabilities
  - Mobility concerns
  - Communication needs
  - Emergency contact information
  - Providing information in advance may help emergency responders better understand and respond to your family's needs during an emergency.

**CLEVELAND**

- **Community Connect -** voluntary online platform that allows residents to share important household information with emergency responders before an emergency occurs. At this time, Community Connect is currently in development for Cleveland County and not yet available to

the public. Additional information will be released once the platform is launced. Once there is a release date, information that may be shared includes: household members, medical needs or disabilities, mobility concerns, emergency contacts, pets in the home, and other information that may help first responders.

  - Contact your local fire department or emergency management agency for information on how to best share information with emergency responders before an emergency occurs.

- **Project Lifesaver** (not currently active in Cleveland County) - program designed to assist in locating individuals who may be at risk of wandering or becoming lost. County partners continue to explore options and assess community interest in future programs that support individuals with disabilities and special health care needs.

- Contact Cleveland County Emergency Management (704-484-4841), the local Sheriff's Office (704-484-4888), or Cleveland County Communications (704-484-4822) to learn about current safety programs and available resources.

**GASTON**

- **Emergency Alert Program** - Get alerted about emergencies and other important community news by signing up for our Emergency Alert Program. This system enables us to provide you with critical information quickly in a variety of situations, such as severe weather, unexpected road closures, missing persons and evacuations of buildings or neighborhoods. You will receive time-sensitive messages wherever you specify, such as your home, mobile or business phones, email address, text messages and more. You pick where, you pick how.

- **Computer-Aided Dispatch (CAD)** is the system used by 911 dispatchers and first responders to manage emergency calls. In some situations, information about a person's disability, medical condition, communication needs, or safety concerns may be available to emergency responders to help them provide more appropriate assistance during an emergency.

**LINCOLN**

- **Project Lifesaver** - Project Lifesaver's primary focus is on citizens with exceptional needs who might be at risk of becoming separated from caregivers. Any Lincoln County resident who is at risk is eligible to participate. The program was created with two goals in mind: to streamline search and rescue procedures and to help save lives. It operates by electronically tracking the client through a transmitter and is a round or oval shaped device that can be worn by the client on the arm or ankle. There is a requested monthly fee of $20 to monitor clients. Funds are used to refurbish transmitter bands, batteries, and supplies for the equipment. A trained representative from the Lincoln County Sheriff's Office will meet with the client and caregiver approximately every 40 days to ensure proper maintenance of equipment and replace batteries and bands. Client records and profiles are kept on hard copy at the Lincoln County Sheriff's Office as well as in the Project Lifesaver database for quick access and response.
- **KIDBASE Program** - KIDBASE helps emergency responders better understand and prepare for the needs of children with disabilities, medical conditions, or other special healthcare needs. Families complete an online KIDBASE form describing their child's needs. An EMS professional will follow up with the family to gather additional information and help determine the best ways to support the child during an emergency.

## Cleveland, Gaston, Lincoln, & Catawba Specific Resources

- **Special Needs Registry** - The Lincoln County Special Needs Registry allows adults with disabilities, medical conditions, or other special needs to voluntarily provide information that may assist emergency responders during an emergency. Adults can self-register through the online Special Needs Registry. Information provided helps emergency personnel better understand individual needs and plan appropriate support during emergencies.

- **Emergency Information Sharing** - Families and individuals are encouraged to keep registry information current and update records whenever contact information, medical needs, or living arrangements change. Contact Lincoln County Emergency Management at 704-736-8660 for additional information about the Special Needs Registry and other emergency preparedness resources available in the community. Contact Lincoln County Emergency Medical Services at 704-736-9385 for additional information about KIDBASE Registry.

## Local Resources by North Carolina County

- **North Carolina Resources by County** - Select your county from the interactive map or from the list of counties to view available resources, including Children's Developmental Services Agency, Family Support Network, First in Families, Employment and Independence for People with Disabilities (EIPD), and county and city school Exceptional Children (EC) offices. Please note that positions and roles change often, so some information may not be current.

## Videos

- **What to Put in a Home Emergency Preparedness Kit**
- **Be Ready : Disaster Preparedness for Families with CYSHCN**
  This in-depth video covers creating a "Go Kit" that includes comfort items, up-to-date medical care plans, and specialized supplies like extra batteries for medical equipment
- **Preparedness for All: Emergency Planning for People with Disabilities,** Centers for Disease Control and Prevention (CDC)

- **Emergency Prepping with a Child with a Disability** - Offers practical tips on using AAC devices with pre-programmed emergency responses and utilizing social stories to help children understand abstract emergency concepts.
- **Helping Children with Disabilities During an Emergency** - A CDC resource focused on keeping children calm and following safety instructions from local authorities.
- **Red Cross Inclusive Preparedness** - Provides emergency information in American Sign Language (ASL) and covers general disaster readiness and home fire safety.
- **FEMA Disability Toolkit** - A series of short videos specifically for people who are blind, hard of hearing, or use wheelchairs, highlighting unique preparedness needs.

## Resources for Medical Providers

- **Region V for Kids Pediatric Disaster Center of Excellence: Professional Resources**

- **Be Ready : Healthcare Provider Tips for Families of Children and Youth with Disabilities & Medical Needs**

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**www.ecac-parentcenter.org**

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